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Report of the Independent Expert on the enjoyment of human rights by persons with albinism on the Regional Action Plan on Albinism in Africa (2017–2021)

Note by the Secretariat

The Secretariat has the honour to transmit to the Human Rights Council the report of the Independent Expert on the enjoyment of human rights by persons with albinism on the Regional Action Plan on Albinism in Africa (2017–2021). The Plan sets out 15 specific and concrete measures centred around four key pillars: prevention, protection, accountability and, finally, equality and non-discrimination. It was developed by the Independent Expert through broad consultations and on the basis of recommendations made by various human rights bodies, in particular those from the Africa region, where all the reported attacks have taken place so far. The Plan is also based on the recommendations of United Nations mechanisms and a wide range of stakeholders, including persons with albinism. Finally, it is also deeply guided by the principle, which is engrained in the 2030 Agenda for Sustainable Development, that no one should be left behind and that efforts to achieve the Sustainable Development Goals should begin with those furthest behind.

(E) 17-22920(E)

Please recycle

Report of the Independent Expert on the enjoyment of human rights by persons with albinism on the Regional Action Plan on Albinism in Africa (2017–2021)*

I. Introduction

1. Since 2006, over 600 attacks and other human rights violations against persons with albinism have been reported in 28 countries in sub-Saharan Africa. Given the relatively small size of the population of persons with albinism and their extreme visibility in this context, those numbers translate into a major threat to their right to life. Moreover, those numbers represent only the cases that have been reported; it is believed that many more cases are not reported, owing, notably, to the absence of monitoring mechanisms. The Regional Action Plan on Albinism in Africa (2017–2021) is a direct response to those human rights violations.

2. The Plan consists of concrete and specific measures that are achievable both immediately and in the short-to-medium term. In addition, it is hoped that it will trigger long-term initiatives. The measures are centred around four key pillars: prevention, protection, accountability, and equality and non-discrimination.

3. The Plan is a concrete initiative to uphold the principle, which is enshrined in the 2030 Agenda for Sustainable Development, of leaving no one behind and to begin with those furthest behind.

II. Methodology

4. In the light of the need to respond urgently to the attacks and related human rights violations against persons with albinism, the Plan was initially put together by the Independent Expert using recommendations from the resolutions of the United Nations and African Union, particularly those of the African Commission on Human and Peoples' Rights, and from the African Committee of Experts on the Rights and Welfare of the Child. Content was also distilled from recommendations made by treaty bodies, by the universal periodic review mechanism and from national responses, such as the multisectoral action plan from Mozambique and Malawi, as well as those made by various national task forces in the United Republic of Tanzania. De facto and de jure national responses from other countries, such as Kenya, Nigeria and South Africa, were also considered.

5. The initial draft of the Plan was scrutinized during consultative workshops, the first of which was a two-day forum entitled "Action on albinism in Africa", held in Dar es Salaam, United Republic of Tanzania, in June 2016, with over 150 participants from 26 countries in the region. In November 2016, a high-level meeting in Pretoria reviewed the proposed plan, which had been updated to reflect input from the consultative forum in Dar es Salaam. Furthermore, in November, a think tank, which was elected at the end of the consultative forum, met in Nairobi for two days to refine the proposed plan. The participants at those workshops represented officials from various United Nations country teams, the African Committee of Experts on the Rights and Welfare of the Child, the African Commission on Human and Peoples' Rights, civil society, including organizations of persons with albinism, Governments, national human rights institutions and academia. Altogether, more than 200 participants from the majority of countries in the region participated.

6. A panel and a side event were also organized during the 60th ordinary session of the African Commission on Human and Peoples' Rights to discuss the Plan further, which led to the adoption of resolution 373 (LX) 2017. In addition to endorsing the Plan, the Commission, in its resolution, urged all States parties to the African Charter on Human and

* Circulated in the language of submission only. The annex is being issued without formal editing.

Peoples' Rights to take all the measures necessary for its adoption and implementation and invited the relevant organs and bodies of the African Union to give due regard to adapting and implementing the Plan.

III. Implementation and monitoring

7. The Plan is to be launched online to improve access, mobilize support and systematically monitor achievements and best practices to promote replication, identify gaps in implementation, avoid unnecessary duplication, and advance cooperation from a variety of stakeholders in the context of Goal 17 of the Sustainable Development Goals (partnerships for the goals). In that regard, it will be crucial for national Governments to have a focal point on the issue, who could be from an existing ministry or an interministerial body, to ensure effective and sustainable execution.

IV. Specific measures

8. To encourage widespread dissemination, comprehension and, above all, implementation of the Plan, the measures have been kept simple. It is also the goal of the Independent Expert that the Plan will spur the development of detailed national action plans, for which the Plan can act as both a standard and a measure, providing a framework for a contextual and holistic response at the national and community level.

Annex

The following definitions are used in the description of the Plan

(a) **PWA**: Persons with albinism
(b) **Stakeholders**: every relevant group or body including state, civil society, national human rights institutions, regional and international human rights and development mechanisms.
(c) " "I": Immediate term, "S": Short term = 1 to 2 years, "M." Medium term = 3 to 5 years, "L." Long term = immediate and on

Regional Action Plan on Albinism in Africa (2017-2021)

5-year plan to address attacks and related violations against persons with albinism in Sub Saharan Africa
"Leaving No One Behind: Starting with the Furthest Behind First"

A. Prevention measures

	Priority area	*Responsible Party*	*Time Frame*	*Ideas on How / Comments*
1	Public education and awareness raising campaigns, sustained (and not ad hoc) for at least 2 years	All stakeholders	I to S	Demystify albinism through creative use of media. Involve faith based organizations and traditional healers, family members and PWA. Appoint PWA in high status roles. Replicate image of PWA in public materials. Use both traditional and social media. Train media personnel on the issue.
2	Data collection: disaggregated data and needs assessment (including security needs)	State	M to L	Census should allow people to choose "albinism" specifically from lists. Disability, health and education sectors can also proactively gather data.
3	Root causes – identify and address	State with support of other stakeholders with specialized knowledge and investigative techniques	I to M	Conduct research – legal, anthropological, academic and other forms - on root causes[1] and address them. Research should include cross border trafficking in body parts.

[1] Root causes identified in report of UN Independent Expert include misbeliefs on albinism, witchcraft, weak law enforcement, gap in laws related trafficking in body parts as well as ambiguity in witchcraft and traditional medicine laws and practice. See [2] Report of the Independent Expert on Enjoyment of Human Rights by Persons with Albinism, Root causes of Attacks and Discrimination against Persons with Albinism - A preliminary Survey, 27 July 2016, A/71/255.

B. Protection measures

	Priority area	*Responsible Party*	*Time Frame*	*Ideas on How / Comments*
1	Effective law enforcement in response to attacks and violations against persons with albinism	State	I to M	Training and, resourcing all law enforcement personnel including border guards. Strengthening community based protection structures beginning with traditional authority. Reinforcement of structures of homes and living environment. Equip PWA with security tools.
2	Review legislative framework including with regards to trafficking of body parts and witchcraft as well as traditional medicine and recognize "colour" as a ground of discrimination	State	I to L	Review criminal law framework for adequacy in response to attacks and violations against PWA. Encompass trafficking in body parts as high crime. Prevent witchcraft related crime. Regulate practice of traditional healers. Include colour as a prohibited ground of discrimination.
3	Health Care workers and midwife training	State & all stakeholders	I to M	Train on albinism and early intervention particularly linked to vision impairment and skin cancer (including preventive and curative measures). Particular focus on women with albinism and mothers of children with albinism
4	Social welfare schemes should include PWA	State	I to L	Social welfare programs, legal aid, poverty alleviation programs etc.
5	Monitoring and Reporting – support the work of civil society	State & all stakeholders	I to L	Support civil society with resources. Include them in all processes & programs relating to them. Allow civil society space

C. Accountability measures

	Priority area	*Responsible Party*	*Time Frame*	*Ideas on How / Comments*
1	Combat impunity; Prioritize prosecution of cases of attacks	State	I to M	Train prosecutors & investigators through handbook (existing best practice). Issue sentencing guidelines, and assign cases to higher Courts. Resource prosecution, law enforcement and investigation officers. Appoint special prosecutor.
2	Victim support	State & all stakeholders	I to M	Psychosocial, medical, legal and socioeconomic support to rebuild the lives, for both victims, and surviving relatives. Should be available at community level
3	Re-integration of the displaced	State & all stakeholders	I to M	Process should be executed by team consisting of both community and international development agencies. Carry out security assessment and public education before reintegration. Act in the best interest of the child.

D. Equality and non-discrimination measures

	Priority area	*Responsible Party*	*Time Frame*	*Ideas on How / Comments*
1	Create post or officer on albinism in disability ministry or other human rights framework nationally	State	I to L	Officer can be housed in general department on disability, health, and/or marginalized/minority groups to ensure implementation of measures in this Plan among others
2	Vision: Reasonable accommodation (education and workplace)	State	I to L	Provide and ensure adaptive devices and vision support in class and workplace including copies of teachers/student notes as needed. Include PWA in disability policy and benefits.
3	Skin cancer : access to adequate health care	State	I to L	Provide system wide distribution of sun protection creams and provide cancer, and pre-cancer treatment at no cost. Reimburse cost if distance to care is far from residence. Ensure no standing in the sun for school, work or access to government services. Use mobile clinic (best practice).
4	Intersectionality principle should apply	State and all stakeholders	I to L	Address and incorporate intersecting issues relating to women, children and issues of discrimination based on colour